Utah Department of Health

News Release

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Utah Newborns to be Tested for Cystic Fibrosis

Newborn Screening Program now tests for 36 genetic disorders

SALT LAKE CITY – As many as 25 babies born in Utah this year with cystic fibrosis (CF), or who carry the CF gene, will be diagnosed early thanks to the expansion of the Utah Department of Health's (UDOH) Newborn Screening Program. The program screens blood samples from approximately 55,000 newborns every year and identifies nearly 500 babies who are born with 36 different genetic disorders.

"Often times diseases are not detected and diagnosed until symptoms actually begin to present themselves, which unfortunately could be too late to prevent disability or death," said UDOH Executive Director Dr. David Sundwall. "The Newborn Screening Program is critical to the early detection of disease and allows doctors to provide treatments that will help ensure these babies lead fuller and healthier lives as they grow up."

Cystic fibrosis is the most common life-threatening genetic disorder in the United States, affecting the lungs and digestive systems of approximately 30,000 children and adults. The disease occurs when a defective protein disrupts the normal function of cells which line the sweat glands and passageways inside the lungs, liver, pancreas, and digestive and reproductive systems. The disease causes the body to produce thick mucus that can clog the lungs and lead to life-threatening infections, or obstruct the pancreas and stop natural enzymes from helping the body break down and absorb food.

In the 1950s, few children with cystic fibrosis lived to attend elementary school. Currently, the life expectancy for people living with the disease is close to 38 years. The Intermountain Cystic Fibrosis Center at Primary Children's Medical Center estimates

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that 240 children and 160 adults in Utah live with the disease. Among them are David Parkinson's four-year-old daughter Eliza and six-year-old daughter Tessa.

"The key to battling cystic fibrosis and the resulting malnourishment and fatal lung infections resulting from the condition is through early diagnosis and prevention," said Parkinson, who also chairs the Utah/Idaho Chapter of the Cystic Fibrosis Foundation and serves on the UDOH Newborn Screening Advisory Committee. "More often than not, diagnosis comes in the emergency room, where a child presents with persistent lung infections, lung damage, and malnourishment, all of which could have been avoided with early diagnosis."

With early detection and diagnosis, families will be able to obtain genetic counseling and treatments for their babies, giving them a head start in their battle with the disease.

"The Department of Health worked very effectively with the community and local and national experts to develop an innovative cystic fibrosis screening program," said Dr. Jeff Botkin, a physician and chair of the Newborn Screening Advisory Committee. "While most states are screening for cystic fibrosis, we believe the approach adopted by Utah will be a model for other states around the country."

The UDOH extends its appreciation to the many partners who worked tirelessly to add cystic fibrosis to the Newborn Screening Program, including: Dr. Barbara Chatfield of the Intermountain Cystic Fibrosis Center at Primary Children's; Dr. Dave Viskochil of the University of Utah's Division of Medical Genetics; the March of Dimes; and the volunteers who serve on the UDOH Newborn Screening Advisory Committee and the Genetics Advisory Committee.

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The mission of the Utah Department of Health is to protect the public's health through preventing avoidable illness, injury, disability and premature death; assuring access to affordable, quality health care; and promoting healthy lifestyles.